



Representative Louise M. Slaughter
Chairwoman, House Committee on Rules
Representing New York's 28th District

PRESS RELEASE

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Rep. Slaughter, Author of Genetic Information Nondiscrimination Act, Celebrates Bill Signing

After 13 Years, Legislation Ushers in "New Era in Health Care"

Washington, DC – Congresswoman Louise M. Slaughter (D-NY-28), Chairwoman of the House Committee on Rules, celebrates the Genetic Information Nondiscrimination Act being signed into law at today's White House bill signing ceremony. Rep. Slaughter, a microbiologist with a Masters in Public Health, authored and first introduced genetic antidiscrimination legislation thirteen years ago.

The Genetic Information Nondiscrimination Act (GINA) prevents health insurers from canceling, denying, refusing to renew, or changing the terms or premiums of coverage based solely on a genetic predisposition toward a specific disease. The legislation also bars employers from using an individual's genetic information when making hiring, firing, promotion, and other employment-related decisions.

“This is a tremendous victory for every American not born with perfect genes – which means it’s a victory for every single one of us,” said Rep. Slaughter. **“Since all of us are predisposed to at least a few genetic-based disorders, we are all potential victims of genetic discrimination.”**

“Today marks the beginning of a new era in health care,” continued Slaughter. **“Americans can finally take advantage of the tremendous potential of genetic research without the fear that their own genetic information will be used against them.”**

The Senate unanimously passed the bill on April 25, 2008. The measure won House approval by an overwhelming margin of 414-1 on May 1, 2008.

BACKGROUND

Rep. Slaughter introduced the first genetic antidiscrimination bill in 1995. However, it took the new Democratic Congress to make protection of genetic information a national priority.

During the 110th Congress, Rep. Slaughter, along with Rep. Biggert (R-IL-13), Rep. Eshoo (D-CA-14), and Rep. Walden (R-OR-2), introduced H.R. 493, the Genetic Information Nondiscrimination Act on January 16, 2007. In April 2007, the House passed H.R. 493 by an overwhelming vote of 420 -3. The House reaffirmed its support on March 5, 2008 when it passed the Paul Wellstone Mental Health Parity Act, which included GINA within the legislation.

The Senate had passed this bill unanimously twice in previous Congresses. However, during the 110th Congress, there was a hold placed on the bill in the Senate. The yearlong hold was released after lengthy negotiations ended in late April.

Support in the White House: On April 25, 2007, the Bush Administration issued a Statement of Administration Policy (SAP) in support of H.R. 493.

Historical Precedents Indicate Need for Legislation: In the 1970s, many African-Americans were denied jobs, educational opportunities, and insurance based on their carrier status for sickle cell anemia, despite the fact that a carrier lacked the two copies of a mutation necessary to get sick.

In 1998, Lawrence Livermore Laboratories in Berkeley was found to have been performing tests for syphilis, pregnancy, and sickle cell on employees without their knowledge or consent for years.

In 2000, the Burlington Northern Santa Fe Railroad performed genetic tests on employees without their knowledge or consent.

Broad Public Support: In 2002, 85 percent of those surveyed by the Genetics and Public Policy Center at Johns Hopkins University did not want employers to have access to their genetic information. By 2004, that number had risen to 92 percent. In 2002, 68 percent of those surveyed said their genetic information should be kept private from health insurers. By 2004, it had increased to 80 percent.

Broad Support Among Health Care Professionals: In one survey of genetic counselors, 108 out of 159 indicated that they would not submit charges for a genetic test to their insurance companies primarily because of the fear of discrimination. Twenty-five percent responded that they would use an alias to obtain a genetic test so as to reduce the risk of discrimination and maximize confidentiality. 60 percent indicated they would not share the information with a colleague, because of the need for privacy and fear of job discrimination.

Over 500 health, medical, and scientific organizations have endorsed GINA.

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